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ABSTRACT

Intended for South Carolina families with a child having mental retardation, this guide encourages families to participate in all aspects of programs and services and offers guidelines for working with professionals. Five to 30 suggestions or tips are listed for each of the following aspects: (1) learning that your child has special needs (e.g., refuse to be a victim and seek information); (2) stressful periods for families with special needs (e.g., initial diagnosis of mental retardation and beginning public school); (3) working with professionals routinely (keep copies of all information and remember that you are the final decision maker); (4) resolving conflict (be a good listener and speak for yourself and your child); (5) developing effective partnerships (share respect, decision-making, feelings, flexibility, and honesty); and (6) becoming involved (serve on the local mental retardation board and help other parents). A "Parent's Bill of Rights" and "Commandments for Families with Special Needs" complete the guide. An appendix contrasts traditional and state-of-the-art views on perceptions of disability and family roles and contrasts myths and realities about the decision-making process. (DB)

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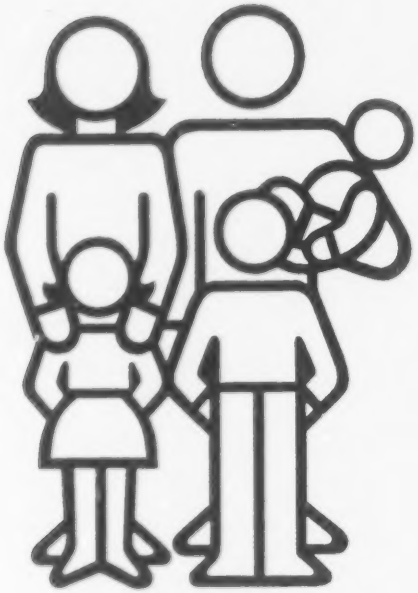

Working With Professionals

A Guide for Families With Special Needs

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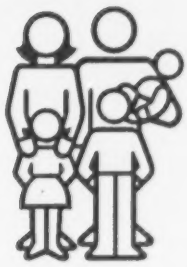

Working With Professionals

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Working With Professionals

The S.C. Department of Mental Retardation encourages families to participate in all aspects of programs and services for individuals with mental retardation or related disabilities.

This guide provides information for families, so they can work together with professionals who provide services for their child. It was written by the parent of a child with mental retardation who is also a professional at DMR, and is based on experience in both areas.

Families should participate in planning services, making decisions and advocating for people with mental retardation. They know their family member best and see the person's strengths and challenges, likes and dislikes. Families hold their child's vision for the future.

Learning That Your Child Has Special Needs

When we, as parents, learn about obstacles in our child's development, the information comes as a tremendous blow. One mother described her experience as entering a dark tunnel with little hope for the future.

Family experiences are unique, but families often have common questions, when learning of their child's special needs:

- What caused my child's disability?
- Did I do anything to cause my child's disability?
- What did I do to deserve this?
- How could God allow this to happen?
- What will my child be able to do?
- Will my child need support forever?
- Who will take care of this child when I am gone?
- How will this child's disability affect my marriage?
- How will my spouse, my other children, my family and friends accept this child? Will they love my child?
- Will I be able to provide for my child's needs? Will I be a good parent?
- Can I love this child?
- Will my child outgrow these special needs?

When learning that your child has a disability some common reactions include:

Denial - "This cannot be happening to me, to my child, to our family."

Anger - Aggression toward the child, professionals or family members.

Fear - Suspicion of the unknown and future.

Guilt - Concern about what caused the problem.

Confusion - Not fully understanding terminology or events. Confusion results in inability to make decisions.

Powerlessness - Inability to change what is happening.

Disappointment - Imperfection poses a threat to their sense of self and values.

Rejection - Rejection directed at the child, personnel or family. Some parents report a "death wish" for their child.

It is important for families to identify all feelings that can arise, so that they will know they are not alone.

What is different about parenting a child with special needs? Nothing really. Your child—like all children—needs love, understanding, security, discipline and care. You may need more energy, patience, understanding, stamina, know-how, assistance, financial resources, time and emotional support. At times, you may feel more stress, isolation, guilt, inadequacy, helplessness, despair and pain. Putting these factors aside, there is a great deal of joy in parenting a child with special needs.

Crisis and change are a basic part of all people's lives. How we deal with these events determines whether we feel defeated or stimulated to grow. While we may have little control over crises that come our way, we have the freedom to choose how we will respond.

Every person and family has strengths. Sometimes we are not aware of those strengths, because we are busy dealing with everyday crises. Sometimes we need to recognize our strengths. Then when problems mount, we can use them to handle problems more effectively. Here are some things you can do to help your perception of your family's strengths:

- Keep in touch with reality. Recognize that there are things we can change and others we cannot. When problems occur, many people see life through a single portion or a slice only. Develop a broad outlook.
- Refuse to be a victim. After being confronted by problems, some people think they are unable to solve problems or manage events. Consequently, they become passive and tumble into depression.

- Look at change as a challenge. Uncertainty is the one certainty of life. Change comes to all. Those unwilling to accept change and view it as a challenge will find themselves frustrated or even broken.

- Focus on strengths, not weaknesses. Concentrate on potential and not limitations.

- Try not to compare what your child does with what others can do. Look for and appreciate your child's own strengths and contributions.

- Choose to grow. Every problem brings the potential for growth. We should approach challenges creatively and try to turn them to our advantage.

- Balance self-concern with concern for others. Personal healing comes as a result of helping others. Reaching out with compassion allows you to stay engaged in life.

- Maintain a sense of humor. Laughter is a good way to release negative tension.

- Talk with your spouse and with other parents. Focus on gaining strength from each other and growing together. List each child's and family's strengths. You may be surprised at the insight others bring.

- Take care of yourself so you will have energy for all the things you must do. It's easy to neglect your own needs. Ask your case manager about respite services and parent support groups.

- Turn to others for support. We know that people who have the support of others, whether in a formal or informal group, have a positive outlook on life.

- You aren't the only one who can care for your child. Share caregiving tasks. Recognize others as an important part of your life.

- Think about what you appreciate about each and every family member.

- Call your local mental retardation board. A case manager will work with you to identify your family's service needs and resources available to address those needs.

- Explore support groups and publications related to your child's needs. Your case manager can help you find a parent support group and other resources in your community.

- Take one day at a time.

- Learn the terminology regarding your child's special needs. If you don't understand what a professional is saying, ask them to explain it in simple terms.
- Seek information.
- Don't be intimidated by people involved in treating or helping your child. Ask questions. Seek second opinions.
- Don't be afraid to show emotion. It's okay to cry.
- Learn to deal with bitterness and anger.
- Remember time is on your side. Time may or may not heal wounds, but it does lessen the pain.
- Avoid judgment. Many people react to serious problems based on a lack of understanding, fear of not knowing what to say, or fear of the unknown.
- Keep your daily routine as normal as possible.
- Remember this person is your child, first and foremost. Your child's disability does not make them less valuable, less human, less important, or less worthy of love and parenting.
- Let go. Throughout life letting go is probably one of the hardest, but most important things to learn to do— day in and day out. You cannot control life. You cannot control every aspect of your children's lives and how they will be. They have their own unique personalities, their own lives to live in their own way. Allow yourself to live.
- Avoid overindulging your child. Give your child opportunities to learn at an early age and don't protect them from challenges. Let them make mistakes and learn from natural and logical consequences.
- Avoid the punishment trap! Punishment can stunt your child's ability to become a self-reliant individual. Constant use of negative reinforcement will lower your child's self-esteem. Reward good behavior and use mild punishment such as behavior penalty, frank discussion about behavior, etc. Seek counseling and resources on proven ways.
- Encourage your child by letting them know how capable and unique they are, giving them opportunities to learn things for themselves, and providing a good education for them.
- Recognize you are not alone.

Stressful Periods for Families With Special Needs

There are ten periods which may cause unusual stress for families with special needs. These periods include:

Differences in Expectations for Child's Development

- Children usually begin walking (12-15 months);
- Children usually begin talking (24-30 months);
- Beginning public school (labeled as different in classroom);
- Puberty (tension between physical appearance and ability; sexuality, fear of pregnancy);
- Twenty-first birthday (symbolic of independence, employment).

Differences in Expectations of Parenting

- Diagnosis of mental retardation or related disabilities;
- Younger siblings surpass the child developmentally;
- Serious discussion of placement outside the home or actual placement;
- Behavior or health problems unique to the child's special needs;
- Serious discussion about guardianship and long-term care for the child.

Source: Adapted from "Chronic Stresses of Families with Mentally Retarded Children" by Lynn Wilker.

Working With Professionals Routinely

Parents and professionals have different relationships with people who have mental retardation. The parents' relationship is personal, lifelong and caring. Professionals' involvement is time-limited and objective. Neither relationship is better, they are different. As with most partnerships, bringing people together with different skills and perspectives can develop a successful relationship.

Key points for working with professionals:

- Seek out professionals and parents who demonstrate concern for you and your family through their actions.
- Learn about normal child development, the nature of your child's disability and possible implications for your child's development.
- Learn your rights and the rights of your child regarding:
  - service eligibility;
  - confidentiality and access to services;
  - informed consent and decision-making;
  - grievance procedures and rights of appeal;
  - policies, principles and standards for providing services.
- Keep a record of all contact with professionals and agencies. Include the date and type of contact, the person's name and title, agency, telephone number (and address where necessary), a summary of important points discussed and details worth recording.
- Keep copies of all information you gather or provide.
- Develop a file of all material related to your child's development and services.
- If access to a professional is difficult:
  - Discuss with the professional at the outset your expectations for access.
  - If you have difficulty setting up an appointment with a professional, request to meet by a certain date and specify how much time you think you'll need.
  - Let the professional know you have problems reaching them and ask what to do to avoid delays.
- Tell the professional what kind of help you want, if you can. If you aren't sure what kind of help you want, let the professional know you reserve the right to decide later.

- Tell the professional you want and expect to be involved in decisions about your child. You may need to anticipate upcoming decisions and request to be involved.
- If a professional uses terms you do not understand, ask them to explain in simple terms.
- Don't give up responsibility for your child or advocating for your child's best interest.
- Know about resources available to you and your child. Be specific with your case manager about your child's and family's needs.
- Learn about the admission criteria, programs, and service goals of all relevant agencies.
- You are your child's best advocate; collect information, stay involved, and participate.
- When scheduling meetings with professionals, clarify the date, time frame, place, purpose, participants and whether you need to bring materials. If you feel unsure about attending a meeting, arrange for another parent or advocate to go with you. Consider meeting at a neutral site, if your setting or the professionals' setting could interfere with agreeing to the best results for your child.
- Before meetings, write down points to be discussed, questions to be answered, and decisions to be made.
- Be on time for all meetings. You may want to make notes of your discussion.
- After attending meetings and conferences, record the date and place, names and affiliations of all participants, information discussed, decisions or disagreement, and the date and details of any future meetings.
- Make sure all commitments include a target deadline and identify the person(s) responsible.
- Remember professionals are people who choose to provide services of a particular nature. For this exchange to be useful, the professional should be a resource to you and your family.
- Involve your child in choosing services when appropriate, and respect their point-of-view.
- Develop relationships with professionals before you need them.
- Believe that all problems have solutions. Allow time to help. Don't give up.
- Remember you are the final decision maker.

Resolving Conflict

You may be angry if you don't think your needs are being met or that professionals are working on your behalf. Take time to discuss these concerns with professionals.

If you and the professional disagree: 1) focus on your child's best interest; 2) emphasize what's right rather than who's right; and 3) begin with areas of agreement and work from there. When your views of "reality" differ, explore both views to understand each other's concerns.

Separate the people from the problem. Problems frequently fall into three basic categories: perception, emotion and communication. If perceptions are inaccurate, look for ways to educate. If emotions run high, find ways for each of you to let off steam. If there are misunderstandings, work to improve communication.

Don't let anger and frustration affect your relationship.

Perceptions

How you see the world depends on where you sit. People see what they want to see. The ability to see situations from another point-of-view can help solve problems. Understanding the other person's point-of-view is not the same as agreeing with it.

One way to deal with differing perceptions is to discuss them openly, without blaming anyone.

Emotions

Recognize and understand the professional's emotions, as well as your own. Why are you angry? Why are they angry? Are they responding to problems from the past?

Talk about everyone's emotions. A good way to deal with anger or frustration is to release your feelings by airing concerns.

Communication

Communication is important in resolving problems. There are three basic communication problems: 1) You may not be **talking** to each other, 2) You may not be **hearing** each other, and 3) You may **misunderstand** each other.

What can be done about these three communication problems?

- Be a good listener. Pay close attention to what is said and ask the person to spell out exactly what they mean.
- Make sure the other person understands you.
- Speak for yourself and your child, not for the other person. Tell how the problem affects you and your child.
- Be knowledgeable.

If you have honestly tried to resolve your differences with the professional and you still believe that they are not meeting your expectations, go to their supervisor and discuss your concerns or request a second opinion.

If you are still not satisfied after meeting with the individual's supervisor, request a copy of the agency's grievance procedures and rights of appeal.

Usually, if you and the professional mutually discuss your concerns and work to resolve them, grievance and appeal procedures will not be needed.

Preventing Problems

The best way to handle problems is before they become problems. Build a working relationship with professionals. Get to know them personally.

The next section will discuss ways to build effective partnerships with professionals.

Effective Partnerships

Parents and professionals have different relationships with the child. The parent relationship is personal, lifelong and caring. Professional involvement with the child is time-limited and objective. Neither relationship is better; they are different. As with most partnerships, bringing people together with differing skills and perspectives can develop a successful relationship.

Key points for developing partnerships:

- Parents and professionals may have different perspectives, experiences and goals for the child. Sharing and learning to understand these differing perspectives is an important part of care for the child.
- Some decisions are best made by you. Others may require help from a professional.
- To develop a partnership, professionals and family members should balance support and dependence.
- Make sure that you are actively involved in essential aspects of making decisions for your child. Both parents and professionals need to be committed against assuming traditional roles of professionals as knowledgeable decision-makers and parents as passive recipients.
- To build an effective partnership, parents and professionals must share respect, decision-making, feelings, flexibility and honesty.

Involvement

To develop effective partnerships, parents must be actively involved in essential aspects of their child's development and service plan. Parents need to participate in decision-making as members of the program team. Parents are the most important advocates for their child.

If your child lives in a residential setting, you still need to be involved. You should purchase your child's clothing and personal items, participate in staffings, monitor your child's progress and discuss future service needs.

You can also become involved as a volunteer by joining your local MR board parent/family organization, your school's parent/teacher organization and other local advocacy groups. You can participate in these organizations as an advocate for individuals with mental retardation or related disabilities.

Here are some other ways to become involved:

- Serve on your local MR board consumer review team to monitor the quality of services and programs provided by the board;
- Help other parents through support groups, family organizations, etc.;
- Serve as an advocate for another individual with mental retardation who does not have a family member to advocate for them;
- Assist in fund-raising for special projects or needs;
- Promote public awareness to state and local government officials, as well as the news media and public, regarding mental retardation or related disabilities;
- Attend your local MR board meetings and provide advice to the executive director and board members on service delivery, gaps in services and the quality of services provided.

Summary

"All of us have dreams, visions, and anticipations for the future. Like everyone else, people with disabilities and their families have great expectations. Like everyone else, they too need help to be able to have their expectations come true. Professionals and other people without disabilities also need to have great expectations for people with disabilities. Great expectations include feeling control over one's life, a feeling of meaning in one's life, and a sense of one's own value."

Source: Families and Disability Newsletter, Volume 2, Number 1; Spring 1990, Beach Center on Families and Disability.

Today persons bring important gifts to the community. This is true for persons with disabilities, as well as persons without disabilities. Too often, the positive contributions made by people with disabilities have been denied and ignored. We have focused on deficits and negative characteristics and overlooked the gifts and capacities people with disabilities bring to the community. People with disabilities have the ability and right to make contributions and people without disabilities have the right to enjoy the fruits of those contributions. It is for that reason that all of us should create the opportunities in which these contributions can be given and their expectations fulfilled.

We need to work together to build on capabilities, adapt environments, build relationships, help individuals and their families identify what is important to them, and empower them with decision-making and spending authority to act upon those choices.

"Visions, dreams, great expectations—the challenge faces all of us. But only if all of us have great expectations for each other, especially for people with disabilities and their families."

Source: Families and Disability Newsletter, Volume 2, Number 1; Spring 1990, Beach Center on Families and Disability.

Parent's Bill of Rights

- The right not to be blamed.
- The right to understand what's going on.
- The right not to be exploited.
- The right to make or refuse requests from others without feeling selfish or guilty.
- The right to accept help without apology.
- The right to make decisions.
- The right to feel and express anger and other emotions.
- The right to feel healthy competitiveness.
- The right to make mistakes (not the same old ones—but new ones.)
- The right to ask for consideration, help, and/or affection from others.
- The right to tell others what your needs are.
- The right on some occasions to make demands on others.
- The right to request others on some occasions to change their behavior.
- The right to be treated as a capable adult and not be patronized.
- The right to not automatically be assumed wrong.
- The right to take time to sort out your reactions—to not be pressured into an immediate reaction.
- The right not to have others impose their values on you.
- The right to a normal family life.
- The right to live a part of your life that does not include your child.
- The right to fake it from time to time.
- The right to expect miracles.

Sources: Parent Education and Assistance for Kids, Colorado Springs, & Exceptional Parent November/December 1988.

Commandments For Families With Special Needs

- Thou shalt be thy child's best and most consistent advocate.
- Thou shalt share valuable information about your child with professionals who need your input.
- Thou shalt put it in writing and keep a copy.
- Thou shalt try to resolve problems at the lowest level but not hesitate to contact a higher authority if a problem isn't resolved.
- Thou shalt keep records.
- Thou shalt seek out information when needed.
- Thou shalt take time to think through information before making a decision.
- Thou shalt have permission to be less than perfect. Important lessons are learned from both successes and failures.
- Thou shalt not become a martyr. Decide to take a break now and then.
- Thou shalt maintain a sense of humor. It is great for your own emotional well-being and that of your child.
- Thou shalt always remember to tell people when they are doing a good job.
- Thou shalt encourage thy child to make decisions because one day he, or she, will need to do so.

Source: Virginia Richardson, Pacer Parent Training Coordinator

Appendix

Perceptions of Disability

Traditional	State of the Art
People with disabilities are a burden to their family and society.	People with disabilities are valued and contributing members of their families and society.
Families are dysfunctional because of the burden created by the person with the disability.	Society's reaction to and policies about families and disability can create dysfunctionality in families.
Families should have low expectations, expecting segregated services and second-class citizenship, because it's unrealistic for them to expect integrated services.	Families should have high expectations and skills to obtain integrated services and full citizenship.

Family Roles

Mothers are most interested in services for the child.	Every family should have the opportunity to designate appropriate members to take on various roles in the child's life.
Parents of adults overprotect them; so adults should be independent from their parents and rely upon professionals as family substitutes.	Adults with disabilities have the opportunity to identify and act on preferences for family roles.
Siblings should take responsibility for long-term care of their brother or sister, both before and after their parents' death.	Siblings are entitled to normalization and their own lives. It should not be assumed that they will always have a major role regarding their brother or sister.
If any family member is severely "distressed" by the person with a disability, separation from the family is acceptable. The person with a disability should be placed outside the home.	There are many appropriate ways to support the family so it can provide a supportive home to all members, including the person with a disability. Ensuring the person with a disability has a wholesome family life is especially important.

Source: *Supporting Families With a Child With A Disability, Alan Gartner, Dorothy Kerzner Lipsky, Ann P. Turnbull, Brookes Publishing Company, 1991.*

Myths & Realities

Myths about the decision making process:

Myth	Reality
Parents are too emotional.	Because of life experience, parents who choose to participate in making decisions are nearly always realistic and knowledgeable.
Parents are too closely involved.	Because parents are so involved, they make effective decisions. They learn the system out of necessity and can help shape policies and services from their practical needs.
Parents are only concerned about their child.	Parents involved in public policymaking have learned that in helping themselves they may help others.
Parents always want more.	Parents want some control over services for their child with a disability.
Parents don't understand or appreciate funding problems.	Parents are also taxpayers and don't want to increase spending unnecessarily or irresponsibly. They are usually more sensitive to unneeded expenditures.
Parents are troublemakers.	Taking part in decisions that affect the lives of family members is being responsible, not making trouble.
Parents expect too much.	Parents are aware that good programs and services can maximize their children's potential. Approaching that goal for people with special needs is cost effective, since they need fewer services when they gain independence.

Source: "The Speaker", newsletter of Sequin Retarded Citizens Association, 6223 West Ogden Ave., Berwyn, Il, 60402.

Acknowledgments

This guide was developed for families to provide suggestions for working more effectively with professionals of the S.C. Department of Mental Retardation.

To form effective partnerships between families and professionals, there must be mutual respect and joint decision-making, sharing of feelings, flexibility and honesty. Professionals and families need to work together to build capabilities. The challenge faces all of us.

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